



Social Support from the Families of Female Stroke Survivors in Turkey

Türkiye’de İnmeli Kadınların Aileden Algıladıkları Sosyal Destek

İnmede Sosyal Destek / Social Support to Stroke

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Özet

Amaç: Bu çalışma inmeli kadınların aileden algıladıkları sosyal desteğin incelenmesi amacıyla yapılmıştır. **Gereç ve Yöntem:** Veriler sosyo demografik özellikleri belirleyen bir anket formu ve Aileden Algılanan Sosyal Destek Ölçeği ile 36 inmeli kadından toplanmıştır. Verilerin değerlendirilmesinde yüzdelik, bağımsız gruplarda t testi, one way ANOVA kullanılmıştır. **Bulgular:** Aileden algılanan sosyal destek toplam puanının düşük düzeyde olduğu bulunmuştur. İnme sonrası süre uzadıkça aileden algılanan sosyal destek düzeyinin düştüğü görülürken bu ilişki önemli bulunmadı. Medeni durum, algılanan aile desteğini etkilemiştir. İnmeli kadınların eğitimi, mesleği, ko morbid hastalık varlığı, bakım vericilerin cinsiyeti, bakım verenin aileden ya da aile dışından olması, bakım vericinin medeni durumu, eğitim durumu, çalışma durumu ile karşılaştırıldığında aradaki fark istatistiksel olarak anlamlı bulunmamıştır. **Tartışma:** Bu çalışmaya göre, inmeli kadınların sosyal destek almalarının istenilen seviyede olmadığı görülmüştür. Bu doğrultuda inme sonrası birey ve aileye verilen fiziksel rehabilitasyona ilave olarak psikososyal rehabilitasyon programları da verilebilir.

Anahtar Kelimeler

Sosyal Destek; İnme; Aile; Kadın

Abstract

Aim: This study was conducted to determine the social support from the families perceived by women after stroke. **Material and Method:** The data were collected from 36 women with stroke using the Perceived Social Support Scale and a questionnaire determining the socio-demographic characteristics. For the analysis of data, percentages, t-test for independent samples, and one way ANOVA were used. **Results:** Total score of perceived social support from family was found to be low. As the time from stroke got longer, the level of perceived social support from family decreased, while the difference was not significant. Marital status has also affected the perceived social support from family. There were no statistically significant differences were found in terms of women's education, occupation, co-morbid illness, gender of the caregiver, whether the caregiver is from the family, caregiver's marital status, education and employment status. **Discussion:** In conclusion, it was founded that the benefit of the women after a stroke with regard to social support was not at the desired level. In this respect, in addition to the physical rehabilitation after stroke, psychosocial rehabilitation programs for the individual and the family can be designed.

Keywords

Social Support; Stroke; Family; Women

DOI:10.4328/JCAM.1454

Received: 06.12.2012 Accepted: 01.02.2013 Printed: 01.11.2014

J Clin Anal Med 2014;5(6): 480-5

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Introduction

Being the leading chronic disease, stroke is an important cause of morbidity and mortality all over the world [1]. According to the data from the developed countries, stroke, which is the most frequent neurological condition, is the third cause of mortality after heart disease and cancer, and ranks first as a cause of morbidity. [2]. According to the World Health Organization, worldwide 15 million people suffer from stroke each year. Of these, 5 million die and 5 million are permanently disabled [3]. Based on reports from seven countries (USA, France, Germany, Italy, Spain, the United Kingdom and Japan) the incidence of stroke is 214 in 100,000 per year and this rate is increasing with 1.9% per year due to the aging population. This means that, for example in the U.S., every 40 seconds one person has a stroke, and approximately 2,200 people per day suffer from stroke [4,5]. According to some studies conducted in Turkey, the incidence of stroke is 175 per 100,000 people. Calculated according to the country's overall population, annually an average of 125 000 new cases of stroke are encountered. Stroke can affect people of all ages, regardless of gender. However, the majority of stroke cases occur in people over the age of 65 and over the age of 55, the rate of stroke doubles for both men and women for every ten years [6,9].

In case of permanent disabilities, the individual and the family are in need of great support and an intensive training in self-care [10]. The multi-faceted change in the functional status of individual with stroke has also a multi-faceted impact on the caregiver. The presence of a disabled or chronically ill individual in the family, who need continuing care, can create significant problems in particular, depending on the person's role within the family [11]. Illness, disability and death are universal experiences that each individual and family can experience. Anything that affects the family system as a whole also affects the members individually. Serious illness of a member of the family results in a change in homeostatic balance of the family. As in all systems, the homeostatic balance is attempted to be maintained in the family system. To achieve this goal, families develop their own unique and different styles in communication patterns, role flexibility, and boundaries within framework of the sub-system rules and the family rules [12]. The care, treatment, rehabilitation, training, re-acquisition of a profession and the survival of the individual with stroke in an independent way are crucial for the family [13]. Therefore, both the individual and family require an intensive support [14]. One third of these patients are dependent on others in maintaining the daily activities. The patients' quality of life is affected by the degree of dependence and the other complications caused by stroke [13].

Individuals with stroke experience economic and social problems as well as physical and mental disability. Social support is very important for the individual, as the life becomes extremely difficult after stroke. The life will have ups and downs, and the individual will be dependent on various levels. Continuous distress and changing health conditions cause stress in individuals with stroke and their environment. Therefore, social support is not only important for the patient but also for the caregiver and the families. Social support has been reported to fall dramatically in spouses of individuals with chronic stroke with a decrease in the life satisfaction [15]. Social support means that

the basic needs, such as belonging, love, appreciation and self-actualization, which take place in the individual's hierarchy of needs, are satisfied as a result of interaction with other individuals such as friends, family, and professional advisors. Individuals with high levels of social support have been reported to have no feeling of insecurity, which is one of the sources of stress, and to experience less stress than individuals who do not have social support in the same environment [16,17]. In an integrated (holistic) approach to health, stroke patients must be considered together with the relatives. The changes in the life of stroke patients cause also changes in the life of caregivers. Although there are many studies on the positive impact of the social support on the individuals with stroke in the literature, studies in our country on this topic are extremely limited. It is crucial to identify the changing educational needs of the patients and the caregivers from the family after stroke, and to provide the continuity of the care.

This study was conducted to determine the perceived social support of women with stroke. The aim was to define the shortcomings of the social support perceived by the women with stroke and their social environment.

Material and Method

This was a descriptive study, that was conducted to identify the perceived social support of the women with ischemic stroke from their families. The women admitted to Yozgat State Hospital Neurology Outpatient Clinics with an ischemic stroke within the last three months between November 2011 and December 2011, who had no severe disability according to the Barthel index (65 points and above), with no prior history of stroke, with a one-sided lesion, without a speech disorder, not diagnosed with psychiatric disorders, and who agreed to participate were included in the study.

Tools

Scale of Perceived Social Support from Family

Perceived Social Support Scale (PSS-Fa) from Family was developed by Procidano and Heller and the Turkish translation and the validity study was done by Eskin (1993) [18]. The scale consists of 20 items will be answered by checking one of the options: "yes", "no" and "do not know". For each item the response showing the perceived social support is scored as '+1'. Scores range from 0-20. "I do not know" option is not rated. The items 3, 4, 16, and 19 on the scale are expressed reversely. In these questions, the option "no" is rated with '+1' point. The obtained high score indicates a higher perceived social support from family. The Cronbach's alpha internal consistency coefficient is 0.85.

Barthel Index

The Barthel index (BI) is the scale of activities of daily living. The BI is one of the most commonly used disability scales for rehabilitation patients. It evaluates the mobility and self-care activities. [19].

Data Collection

A total of 36 literate women who were admitted to Yozgat State Hospital Neurology Outpatient Clinics with an ischemic

stroke, who agreed to participate in the study were included in the study. A questionnaire was given to all individuals. In the collection of data, the questionnaire form containing information about the disease and the socio-demographic characteristics of patients, and for the assessment of the patients' perceived social support (PSS-Fa) (Eskin, 1993) were used. In this study, the tests were applied using face to face interviews by the researcher, and the application took an average of 10-15 minutes.

Independent variables of the study: Age, gender, marital status, education level, economic status, employment status, duration of illness.

Dependent variables of the study: The patients' mean score obtained from the scale of perceived social support from family. Evaluation of the data

The data was analyzed using the SPSS statistical package program. For the analysis of data, percentages, t-test to analyze the differences between two independent groups and the dependent variable, and one way ANOVA were used.

Ethical Aspects

To begin the study, an official written permission was obtained from the Health Directorate of Yozgat. Patients included in the study were informed about the content and purpose of the research. The participation was done on a voluntary basis. No names were written on the data collection forms. It was stated that the information collected was only to be used for the research.

Limitations of the Study

Limitation of the study is the use of very small number of patients and the random sampling method.

Results

The results obtained from the study investigating the role of perceived social support from family among women with stroke, are presented below. The mean age of women with stroke was 54.5 ± 15.8 years. As to the etiology of stroke, hypertension and diabetes mellitus were the leading causes, each with a rate of 23.8%. The mean age of patients with diabetes mellitus was 57.8 years, whereas the mean age of patients with hypertension was 62.6. Of all the women with stroke included in the study, 78.6% had expenses equal to their incomes. Of the included patients, 63.6% were unemployed housewives, 18.2% were farmers, 36.4% had just a basic level of literacy, and 48.5% had primary education for 5 years. 21.2% were married, while 78.8% percent were single (divorced-widowed). Of all the women with stroke, 73.4% were found to be in 0-6 months of post-stroke sub-acute phase. 54.6% of women have reported that they experience physical and psychological health problems since the event. The mean perceived social support score was 11.45±2.75 (Table 1). The person responsible for the care of women with stroke was the patient's daughter in 42.9%, daughter-in-law in 10.7%, son in 7.1% and the paid female caregivers in 39.3% of the cases. 80% of women with stroke indicated that two or more elderly individuals lived in the same house. The average duration of time of care spent by the caregivers was 12.2 ± 1.12 months (N = 25).

Table 1. Distribution of mean scores of the patients' perceived social support from the families

Scale	Possible upper and lower values	Marked upper and lower values in this study	X±SD
perceived social support from the families	0.00- 20.00	06.00-16.00	11.45±2.75

The mean perceived social support score was 11.1 ± 7.2. PSS-Fa score decreases with increasing age. The mean perceived PSS-Fa score of married women (N=11) was 10.4±2.7, whereas that of the single (widow-divorced) women (N = 25) was 11.4 ± 2.7; the difference was not statistically significant (t=0.83, P >0.005) (Table 2). Of all the women with stroke included in the study, 78.6% had expenses equal to their incomes. 57.9% stated that they did not smoke, whereas 42.1% were active smokers. The mean perceived social support score of non-smokers (11.5 ±2.21) were lessr than that of the smokers (12.2±4.02with stroke (t=0.48, p>0.05).

The lesion area was unknown in 41.6%. The women with a lesion on the left side appeared to have higher scores on social support. There is a insignificants difference in the mean score

Table 2. The distribution of the Means of Perceived Social Support Scores Depending on the Identifiable Characteristics of the Patients with Stroke (n = 36)

Identifiable Characteristics a	n	X ±SD	Significance
Marital status			
Married	7	10.4±2.7	t=0.83
Widow-divorced	25	11.4±2.7	P>0.05
Education			
Primary education (5 years and under)	27	11.0±2.8	t=1.07
Higher education	5	12.0±1.5	P>0.05
Occupation			
Housewife/unemployed	20	10.8±2.6	F=1.226
Farmer	6	10.8±3.1	P>0.05
Other (3 Self-employed, 3 employed for wages)	6	10.2±1.4	
Co-morbide disease			
Hypertension	5	10.8±2.5	F=.245
Diabetes Mellitus	5	12.8±1.0	P>0.05
Other(1 Asthma, 1 rheuma, 1 chronic renal failure, 2 chronic cardiac failure)	5	11.8±3.2	

^aThe means taken out of the available data. 4 data was missing.

of perceived social support from family with regard to the location of the lesion (Table 3). Of all the caregivers of women with stroke, 69.4% were women.

The mean age of the caregivers was 44.5 ± 17.5 years. There were no statistically significant differences in the scores of perceived social support from family with respect to the demographic characteristics of the caregiver such as gender, marital status, education level, employment status, and whether the caregiver was a family member (p> 0.05, Table 4).

Discussion

In this section of the findings of this study were compared with the literature and discussed. In this study, the patient's state

Table 3. The Distribution of Mean Perceived Social Support Scores Depending of the Characteristics of the Disease (n = 36)

Characteristics of the Disease	n	X ±SD	Significance
Brain lesion area a			
Right	10	10.4±2.7	t=2.012
Left	11	12.6±2.3	P=0.059
Duration of Disease			
0-6 months	15	11.2±2.2	t=1.657
6 months and longer	21	10.5±1.3	P>0.05

a 15 patient didn't know to which brain lesion area

Table 4. The Distribution of Means of Perceived Social Support Scores Depending on the Features of the Caregivers

Features	n	X ±SD	Significance
Gender			
Female	24	10.9±2.6	t=1.22 p>0.05
Male	5	12.6±2.9	
Caregiver			
Family member	21	11.0±2.4	t= 0.49 p>0.05
Non-family member, paid caregiver	11	11.5±3.1	
Marital Status			
Married	24	11.1±2.9	t=0.476 p>0.05
Single	5	11.6±1.5	
Education of the caregiver			
Primary education (5 years and under)	23	11.3±2.3	t=0.836 p>0.05
High education	4	11.5±1.9	
Employment status			
Employed	6	12.1±2.2	t=0.920 p>0.05
Unemployed	23	11.0±2.8	

of perceived social support was investigated together with the factors independent from the disease, such as the patient's age, gender, the caregiver's age and the degree of kinship. Especially in acute onset diseases, such as stroke, the sensory and instrumental changes compress the status of the individual and the family, into a short process. The individual and the family should achieve the crisis management skills as fast as possible. Effective problem solving, effective use of external resources in a flexible manner and defining the role distribution after the illness may increase the gains. Otherwise, the patient will be left alone with the adverse impacts of stroke, while the family members of individuals may experience burnout.

The individuals with more social support were found to experience psychological distress to a lesser extent, and to maintain their psychological and physical health even in presence of highly stressful events [20]. As a result of this study, the perceived social support scores of women with stroke were found to be low. Smurawaska et al (1994) (translated by Dayapoğlu and Tan, 2009) have reported that the perceived social support of the female patients was lower than that of the men [21]. A study conducted with the spouses of individuals with stroke revealed that the mean perceived social support scores of women were lower than that of the men [22]. The results obtained from this study are similar to the literature.

The lower perceived social support of women with stroke compared to men is probably due to the women's perception of self-help in the social role distribution, and the continuation of women's traditional care-giver functions after the disease. In

our country, in studies investigating the effect of social support on chronic disease, the social support scores of men were higher, which is similar to our results [23]. In a study of patients with cancer, social support score was found to be higher in males than females. Atlı et al. have found that the overall social support score in cancer patients was similar in both gender, however, the perceived social support from family was statistically significantly higher in men [24]. In their study in patients with COPD, Aras and Tel [25] have also stated that the perceived social support in men was more than women.

The mean perceived social support score of married women (n=11) was 10.4±2.7, whereas that of the single (widow-divorced) women (n = 25) was 11.4 ± 2.7; the difference was statistically insignificant (P <0.005). In a study in cancer patients, Savcı et al [26] have found a higher total score of perceived social support and a score of perceived social support from family in married patients, and the difference was statistically significant for the perceived social support from family. In a study in COPD patients, the perceived family support was higher in the married individuals, whereas friend support was higher in the singles [25]. The higher level of social support of married individuals is probably due to the support of their wives and children, along with the support received from the parents and the siblings. However, in the literature, it is emphasized that marriage is not a stand-alone source of social support, and that there is need for side resources and a happy marriage is an important factor for social support. Incompatible marriages may even cause illness [27].

The perceived social support scores of women with stroke are hardly affected by their level of education. No statistically significant difference was found between the perceived social support scores of the subjects with an education of less or more than 5 years (p > 0.05).

There are studies indicating that low levels of education have negative effects on chronic diseases and the behavior of health improvement. Women with a higher education level take more responsibility for their own health, and their stress management, nutrition, and self-actualization scores are significantly higher [28,32]. This is probably due to the fact that they are better informed about their disease thanks to their higher levels of education and they use it to deal with social support resources. Individuals with a better education also have better financial status and they have ability to establish a network of social relations. In addition, the concept of an individual's health will change in a positive way in parallel with an increase in the level of education, which in turn can contribute to the process of treatment and rehabilitation. At the community level, training programs about chronic diseases and life after the disease can be planned.

In our study, of all the women with stroke included in the study, 78.6% had expenses equal to their incomes, and this group had a perceived social family support score of 11.4±2.6. Statistically there was no difference (p>0.05). Köçkar and Uzun [33] have found higher perceived social support subscale scores in individuals with a high income however, the difference was not significant. Dayapoğlu and Tan [21] have stated that, in stroke patients, scores of perceived social support from family increased with the increasing level of income. In two other stud-

ies in individuals with chronic diseases, it was shown that in individuals with low socio-economic status, the perceived social support from family was low [34,35]. Our results are consistent with results of the literature. Failure to provide material requirements is an important factor in claiming and providing social support. In families, who can only meet their basic needs with their level of income, the perceived social support is low probably they cannot afford their additional maintenance costs and the requirements of social life.

Of all the women with stroke, 57.9% were non-smokers and 42.1% were active smokers. The social support scores of non-smokers were higher ($12.3 \pm .7$) ($p < 0.005$). Smoking itself is a factor that increases the risk of stroke [36], and it also has an impact on the social environment of the individuals. Smokers were found to have fewer abilities in problem solving and social skills [37,38]. The reason of higher social support scores of non-smoking women are probably due to their better use of communication skills.

In this research, 83.3% of the caregivers were women. Altın [39] has concluded that 86.0 % of caregivers of Alzheimer's patients, and 75.0% of the caregivers of depression patients were women. In a study conducted in Europe, more than 50.0% of caregivers were found to be women [40]. Seventy-three percent of caregivers of patients with chronic neurological disease have been found to be women [41]. The results obtained from our study were similar to the literature. In literature, this situation is explained by the cultural acceptance that function of caregiving is related to household and family, which is seen as a natural task for women [42,43]. In this study, 65.6% of the caregivers were one of the family members (daughter, son, daughter-in-law, or grandchild). It was found that 88.9% of the caregivers of Alzheimer's patients were children [39]. It has been observed that the degree of closeness of the caregivers varies among countries. Although various data are available, the majority of caregivers were found to be the children, with spouses on the second place [44,45]. In studies conducted in different cultures [46], it was determined that the majority of caregivers were spouses in Taiwan, and their children in the United States and China. In another study, the vast majority of caregivers were spouses [47].

In this study, 60.6% of the patients included, had stroke for 6 months or longer at the time of admission to the hospital. The reason of this late admission in the chronic phase of the disease is probably due to the frequency of complications. Home care and rehabilitation after stroke should be encouraged. In the acute phase, i.e. in the first 6 months after stroke, the factors that can affect the functional status of patient should be assessed [14].

When the socio-demographic characteristics of caregivers were compared with the level of perceived social support, there were no statistically significant differences in terms of patient's education level, occupation, co morbid illness and duration of the disease; and caregiver's gender, being a family member, marital status, education level, and employment status.

The support of the family members, which is especially important for the chronic diseases, not only ensures the patient's physical and emotional functionality, but also encourages the patient to adopt appropriate behaviors to health and to fully

comply with recommendations of the physician [48,49].

The impact of social support can be reduced by barriers either formed by the individual or from the outside. The establishment of the obstacles affecting the individual is very important to increase the impact of social support [50,53].

Conclusion and Recommendations

It was found that the perceived social support from the family was low. Patients' age, gender, education level, marital status all affected the perceived social support from family. Occupation and employment status of patients, duration of illness, and the demographic characteristics of the caregiver had no effect on perceived social support from family. While the medical treatment of the individuals is carried on after stroke, the nurses prepare for discharge. Post-stroke patients and their caregivers should be evaluated periodically for psychological symptoms and guidance for the maintenance of their social contacts should be provided. By this way, the family caregivers will be included in the process of care, and form a bridge between the community and the hospital, which in turn will lead to a sustainable social support of individuals with stroke. The multidisciplinary stroke team care should take the factors that influence family support into account, while establishing the plans for the patient's care and the treatment.

Competing interests

The authors declare that they have no competing interests.

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